

February 6, 2009

To: Members of the Connecticut Public Health Committee

From: Susan Castonguay

Re: Legislation requiring cystic fibrosis genetic testing

Dear Committee Members,

Eleven years ago on January 8, 1998, my first child, Caroline was born. A mere three weeks later, she was diagnosed with cystic fibrosis. This diagnosis was made because Bristol Hospital, where I delivered Caroline, had voluntarily decided that it would test all children born at that hospital for cystic fibrosis. At that time, eleven years ago, only two states in the United States had legislation requiring all children born in those states to be tested at birth for cystic fibrosis. Those two states were Wisconsin and Colorado. That was then. Today, there are only two states in the United States that do NOT mandate that when a child is born in that state it will be tested for cystic fibrosis. With huge disappointment and tremendous dismay, I am here to inform all of you that those two states are Connecticut and Texas. How, in good conscience, can we justify this denial of needed, essential medical care to Connecticut babies and their families? Every study done in the scientific community demonstrates a clear and significant correlation between the age of diagnosis and longevity for CF patients. With the median age of survival at 37 years, we don't have a single day to waste. We need this legislation immediately.

This week in her speech to the state, Governor Rell stated that she wanted Connecticut to be poised for prosperity when this economic crisis has turned itself around. I, speaking on behalf of all CF parents, say to each of you: I want my child poised in the best possible health when the cure for CF is found. The CCMC pulmonary team advises all of its CF parents that any damage to the lungs prior to the discovery of the cure for CF will be permanent, therefore, parents and CF patients must do everything possible in our power to keep the CF patient's lungs healthy. The number one tool to aid parents in that task is fundamentally information, namely, the knowledge that our children have this disease. Without legislative action, newborn children in Connecticut will, like those in Texas will continue to be some of the most disadvantaged citizens in our country. The question is simple: how much longer will you allow this to continue?

Thank you for your time and attention in this vital matter.

Susan Castonguay

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